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Public Perceptions and Knowledge of Transplantation

by

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Honors Thesis:

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Psychology Department  
University of Richmond  
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## Public Perceptions and Knowledge of Transplantation

## Abstract

**Objective:** Organ transplantation is currently the most preferred treatment method for end-stage organ disease. Despite this fact, the need for transplants is currently higher than the availability of organs, resulting in approximately 20 deaths each day. The objective of this study was to use qualitative research methods to better understand attitudes towards and public knowledge of organ transplantation. **Method:** Fourteen focus groups with 58 participants were conducted by a research team. Thematic analyses were conducted using a phenomenological framework. **Results:** Knowledge of the transplant process was found to play a critical role in one's decision to donate an organ. Individuals may have different attitudes toward living and deceased donation and these attitudes may be influenced by external factors like family, religion, and culture. Certain situations involving closeness, age, and racial/minority status may make an individual more or less likely to donate an organ. **Conclusions:** The findings from the focus groups answered research questions by identifying knowledge, attitudes and scenarios that promote or hinder organ donation. The results can be used to inform interventions and education on the transplant process, and potentially increase the public's willingness to donate organs.

**Keywords:** Organ transplantation, end-stage organ disease, donation, qualitative research

## **Organ Transplantation**

Organ transplantation is currently the most preferred treatment method for end-stage organ disease. In fact, it is known to be the best therapy for terminal and irreversible organ failure, saving lives and improving patients' quality of life (Grinyó, 2013). Additionally, it is sometimes the only available and viable medical option for certain organ conditions (Holman, 2012). Researchers state that solid organ transplantations are essential for developed and mature healthcare systems (Grinyó, 2013). In the past two decades, solid organ transplant programs have been growing and yielding primarily successful results (Grinyó, 2013). Despite these facts, the need for transplants is currently higher than the availability of organs, resulting in approximately 20 deaths each day (American Transplant Foundation, 2019). In fact, more than 6,200 candidates died in 2018 while on the waitlist, without receiving an organ transplant. As of April, 2020 over 112,600 people are in need of a lifesaving organ transplant (UNOS, 2020). Furthermore, waiting list figures underestimate the true need because there are many more who could benefit from organ transplantation but whose condition is not yet grave enough to meet the waitlist requirements (National Academies of Sciences, 2017).

The high mortality rate of those on the transplant waitlist may be in part due to the fact that only 54% of U.S. adults are actually signed up as donors, despite the statistic that 95% claim they are in support of organ donation (U.S. Government Information on Organ Donation and Transplantation, 2017). Researchers have been working on ways to increase the number of organs that are available for transplantation, but the process has been slow to come (National Academies of Sciences, 2017). In hopes of increasing the amount of successfully transplanted organs, researchers have been conducting studies on deceased organ donors and on organs that have been recovered from deceased organs (National Academies of Sciences, 2017). Current mechanisms for

expanding the donor pool include increasing donor registrations and promoting living donor transplants (Deroos et. al, 2019). Even with these mechanisms, researchers predict that the donor pool will likely shrink in coming years because of US demographics and population health problems like obesity, further intensifying the disparity between donors and recipients (Deroos et. al, 2019)

Because the number of people awaiting transplants is increasing each year, there is a need to identify factors that promote or prevent the public from donating organs (UNOS, 2019). A study conducted in 2013 found that lower willingness toward both deceased and living organ donation was attributed to religious beliefs and perceived risks to the donor among the study subjects (Mithra et. al, 2013). The researchers concluded that requirements for the success of a transplantation program are awareness and positive attitudes of the public toward organ donation (Mithra et. al, 2013). Other researchers have found that the transplant process is complex and depends on a number of factors including, individual attitudes towards donation, social structures, cultural practices and religious beliefs (McGlade & Pierscioneck, 2013). It has also been found that knowledge of the transplantation process plays a role in one's decision to donate or not donate an organ.

### **Public knowledge of transplantation**

Prior knowledge regarding the transplantation process has been shown to increase willingness to donate organs. In fact, one of the main factors that could affect one's donation decision is the amount of information they have on the topic (Holman, 2012). A systematic review published in 2012 found that when asked about the organ donation process, participants often referred to "urban myths" or discussed how donation was depicted in television shows (Irving et. al, 2012). Furthermore, many participants noted that they would like more information

on the donation process (Irving et. al, 2012). Other researchers found that general knowledge of transplant medicine, knowledge of who can become a donor, and knowledge of the purpose of organ donor cards facilitate the decision to donate an organ (Rumsey, Hurfurd & Cole, 2003). Rumsey and colleagues (2003) concluded that knowledge of the process allows individuals to disprove false beliefs, which ultimately can increase willingness to donate organs.

A number of other studies have shown that there is a positive association between knowledge of organ donation and ultimate donation behavior. A study that surveyed 2,056 respondents on the telephone revealed that while 94% of the population had heard about organ transplantation, only 19% of these people carried donor cards (Manninen & Evans, 1985). The authors concluded that although some people are very enthusiastic about organ transplantation, they still may not be willing to donate organs, revealing a significant knowledge gap (Manninen & Evans, 1985). A similar study was conducted with medical students in Puerto Rico. Researchers found that while medical students have a positive attitude toward organ donation, substantial lack of knowledge is a barrier to taking the necessary step to become a donor (Marqués-Lespier et. al, 2013).

Education plays an important role in helping to influence attitudes toward organ donation. One study conducted in 2013 found that helping people understand the difference between informed and presumed consent and how the law operates with regards to donation markedly improved attitudes (McGlade & Pierscionek, 2013). Other researchers concluded that the public should not be blamed for being unwilling to donate organs, but rather that the healthcare system and healthcare education providers are responsible for not educating the public on the process (El-Shoubaki & Berner, 2005).

Previous research has suggested more effective approaches regarding health education of the organ donation process (El-Shoubaki & Berner, 2005). El-Shoubaki and Berner (2005) concluded that offering incentives or rewards for organ donation is one way to encourage people to donate. Another study revealed that advanced training of healthcare professionals is another way to potentially overcome organ shortage (Manyalich, Guasch, Paez, Valero & Istrate, 2013). Courses with new training tools were implemented with over 3,000 healthcare professionals. This training included three educational levels: Essential in Organ Donation, Professional Training for Junior Transplant Coordinators, and Organ Donation Quality Management. This specialized training proved to be effective in the increase of patient organ donation in the selected European target areas. This study identified areas for needed education in healthcare professionals and there was significant improvement in both numbers of utilized donors and organs recovered after training (Manyalich,, Guasch, Paez, Valero & Istrate 2013).

An experiment conducted in 2015 found that in-house coordinators from organ procurement organizations may also improve conversion rates for organ donation (Salim et. al, 2015) In the experiment, an in-house coordinator program was started at a hospital. Data regarding organ donation demographics and family consent rates were compared before and after the institution of the IHC program. The in-house coordinators worked to assess potential donors, provide timely referrals, educate hospital staff, and support families. Results showed that coordinators were associated with a significant increase in referrals per day (Salim et. al, 2015). The presence of one trained donor coordinator within every hospital was found to be a key factor to eventually increase donation rates. Authors concluded that an in-house coordinator program should be considered to bridge the gap between organ supply and organ demand (Salim et. al, 2015).

**Attitudes towards transplantation**

The current process of organ donation in the United States is reliant on altruism or voluntary consent (Boland & Baker, 2010). The presence of positive and negative attitudes regarding transplantation can determine a person's commitment to organ donation (Rumsey, Hurford & Cole, 2003). Rumsey and colleagues' (2003) findings indicated that four variables impacted attitudes towards donation: education of the transplant process, knowledge of someone who donated an organ after death, knowledge of someone who received a donated organ, and religious beliefs (Rumsey, Hurford & Cole, 2003). Other factors that affect positive attitudes towards organ donation include relational ties, cultural beliefs, family influence, and body integrity (Irving et. al, 2012).

There are a number of studies that touch on factors that make people more or less likely to support organ donation. A study in 2010 conducted with female college students revealed that the majority of students believed in organ donation if any only if the deceased donor has physically signed an organ donor card (Boland & Baker, 2010). Results indicated that the students had mixed feelings towards organ donation. For example, participants were asked the top three reasons why they would or would not donate an organ for transplantation. The top three reasons given not to donate were: wanting to make sure they are dead before their organs are harvested, fears that organs will be taken before death, and believing that they would not get medical treatment if they were a donor. The top three reasons to donate included: to save a life, to give a better quality of life, and medical research. Participant attitudes towards giving and receiving organs varied, as well as their intended behaviors. Furthermore, their knowledge of the process was minimal (Boland & Baker, 2010).



Lack of knowledge and ultimate fear and mistrust in the minds of the public results in a more negative attitude toward organ transplantation (Mithra et. al, 2013). A set of focus groups conducted with potential donors in 1985 found that primary reasons for not signing an organ donor card were “hastiness of organ removal, mutilation, fatalism, or superstition” (Cortlett, 1985). Another study conducted in 2012 found similar results that beliefs likely to discourage donation included: lack of body dignity for donors, fear of medical neglect for donors, and. need for body wholeness (Irving et. al, 2012). Other major reasons included religion, family attitudes, age, and that the participant had just never thought of it (Irving et. al, 2012). Researchers have proposed that behavioral commitment to organ donation occurs when strong positive attitudes toward donation exist and no negative attitudes toward donation are present (Mithra et. al, 2013).

It is important to note, however, that attitudes do not always lead to congruent behavior. For example, a study conducted in the Bronx, New York indicated strong support for organ donation across racial groups, but revealed discrepancies in the awareness of and attitudes toward organ donation (Yuen et. al, 1998). In fact, none of the African American participants and just 3% of the Hispanic participants had signed an organ donation card (Yuen et al., 1998). Researchers concluded that making it easier for racial minorities to obtain organ donor cards could potentially increase rates of consent regarding organ donation (Yuen et. al, 1998). They suggested that in order to successful increase organ donation rates among minorities, every step of organ procurement must be examined and maximized. Furthermore, this process requires collaboration between doctors, healthcare workers, families, and community leaders (Yuen et. al, 1998). A more recent study conducted among the general public of Karachi, Pakistan found that while positive attitudes towards organ donation were found in 75.2% of the population, only 8.4% of the population would donate irrespective of circumstances (Khalid, Khalid, Muneeb, et.

al, 2019). Furthermore, 43.5% of respondents were unsure if their religion allowed organ donation, which researchers found to be a shocking dilemma (Khalid, Khalid, Muneeb, et. al, 2019). It is important to note, however, that this study only shows attitudes and knowledge of a small population in Pakistan. More than half of the respondents happened to be students and female, so the results do not represent masses of Pakistan or the larger public (Khalid, Khalid, Muneeb, et. al, 2019).

While there are a number of studies on attitudes towards transplantation, there are no known studies on attitudes toward living organ donation in the United States. Pradel noted that further research should address the attitudes of individuals who have not already made their decision to give or accept a kidney or those who have not started to consider a living transplant (Pradel, 2003). Because studies have shown that there is a positive association between knowledge of organ donation and ultimate donation behavior, there is a need for further research on the public knowledge of the transplantation process. This research could help future professionals provide the public with the information they need to make informed decisions regarding donation. Additional research on the public perceptions of transplants would help determine what factors or scenarios influence attitudes toward organ transplantation and ultimately work to reduce the gap between the number of people on the waitlist and the number of people donating organs. The current study expands on previous research by addressing both living and deceased donation, as well as specific scenarios in which an individual is likely or unlikely to donate an organ.

The aim of the current study is to use qualitative methods to answer the following research questions: (1) What factors influence attitudes toward organ transplantation? (2) In what situations are people likely to donate an organ? (3) What do people know about organ transplantation? The

experiences of undergraduate students and community members will be compared with the aim of identifying differences based on generations.

### **Method**

The proposed study is part of a larger project. This qualitative study focused primarily on better understanding attitudes toward and public knowledge of organ transplants. The ultimate goal of the larger project is to use the findings from the current study to inform the development of a psychometrically sound questionnaire. This study and its recruitment methods were approved by the appropriate university (IRB #URIRB181115).

### **Participants.**

Purposeful sampling was used to gather in-depth data from 58 participants. Participants were at least 18 years old, English speaking, and able to read and comprehend study materials. Participants under the age of eighteen and those with severe cognitive impairment were excluded from the study. Participants were recruited from a student pool at the small liberal arts college in Southeastern, US and people from the community. Student participants were recruited from the psychology pool of students and received course credits for their participation in the study. The community sample was recruited from a community in the Southeastern, US via social media, flyers, and online newsletters. Participants were compensated \$20 dollars each for participation in the focus group.

### **Measures.**

Focus groups were conducted to gather information from participants. The research team developed a focus group protocol with open-ended questions, which was pilot tested prior to recruitment. Some examples of questions included: (1) What challenges do patients trying to get a transplant face? (2) Can you tell me what you know about living donor transplants? (3) In what

ways does your family background affect your thoughts on organ donation? The full focus group protocol is available in Appendix A.

### **Data Analysis Plan.**

The focus groups were audio-recorded and transcribed verbatim. The research team adhered to COREQ guidelines (Tong, Sainsbury & Craig, 2007) and Levitt et. al (2018) recommendations. Transcriptions were loaded into the mixed-methods software, MAXQDA, for analysis. Themes were derived from the data upon analysis and thematic analyses were conducted using a phenomenological framework. This framework is an approach to qualitative research that focuses on the commonality of a lived experience within a particular group (Isaacs, 2004). The goal is to arrive at a description of the nature of the phenomenon. The data were analyzed until data saturation was achieved. Each transcript was coded by three separate coders, to check for intercoder reliability. Of the three transcripts analyzed thus far, there is high intercoder reliability with percentages of 100, 93, and 91. The use of verbatim transcripts and diverse recruitment samples increased the credibility of the results. Dependability was established through peer discussion of findings and the review of categories as developed.

## **Results**

### **Sample characteristics**

58 participants were involved in 14 focus group sessions conducted over the course of approximately six months. Six of the focus groups consisted of 29 members from a small liberal arts college in the Southeastern, US. The majority of the student sample were females ( $n=22$ ) with ( $n= 7$ ) males. Participants reported their race as follows: White (55%), Asian (24%), Black (13%), Hispanic (3.5%) and Mixed-Race (3.5%). The mean age of the participant was 20 years ( $SD= 1.33$ ). The remaining eight focus groups consisted of ( $n= 29$ ) community members. The

mean age and demographics of the community focus groups cannot be reported due to disruptions in access to this information due to the COVID-19 pandemic.

A summary of the data indicated: (1) participant gaps in knowledge of the transplant process, (2) differences in attitudes toward deceased or living donation, (3) external influences on participant attitudes toward donation, and (4) specific situations that effect individual's likelihood to donate. A pictorial representation of these components is shown in Appendix B. Specific themes based on these main subject areas are outlined below:

### **Knowledge of Transplant Process**

**Prior knowledge.** All participants reported that they felt they did not know enough about the topic, as evidenced by this quote, "I think it's pretty interesting, though I don't know anything about it." One male community member commented, "My uncle is looking for a kidney, I am a match and I want to know more information." As a whole, there were variations in participants' report of their knowledge of organ transplantation. One participant said,

"I know a little bit about it, just because my uncle basically passed away from it. I just know that kidney failure causes your system, like everything to shut down. I mean that's basically all I know about it."

In addition to personal experience, some of participants' limited knowledge came from the media and television. For example, one female community member commented,

"I don't know very much. Sometimes I pick up information from, embarrassingly, watching soap operas."

A male undergraduate student said,

"I think the most we know is like off of like medical shows. Like that's the only way I know some of these things honestly. In all medical shows they'll refer to the list, "they're

not on the list” or “they’re not high enough on the list.” I think that’s the most we know really.”

In regards to social media, a female undergraduate said,

“I think a big thing is social media. You see all these videos about people getting organ transplants and they make a big, long video about it. I see those on Facebook a lot.

One male community member said,

“I got all my information from the media, and it’s not 100% reliable, coming from TV shows, or, you know, comedy segments.”

The group, as a whole, was inquisitive and wanted to learn more. In one focus group, a participant asked the group facilitators, “If I die, do all of my organs get used? Do they save my organs? Can they save them? How much waste is there?”

**Barriers to sufficient knowledge.** Participants mentioned a number of barriers to sufficient knowledge of the transplant process. Many participants stated that they believed the public does not search for information on donation until it personally affects them as evidenced by the following quotes:

“I feel like I’m a relatively educated person, and I can’t answer these questions. I think most people become educated when it becomes an issue, but they don’t need to most of the time,” a male community member said.

“I think it has to do a lot with the fact that people don’t really care. It seems like with this type of situation, you don’t care unless it happens to, you know, you, or someone you’re close to,” a female community member said.

The group frequently mentioned that the first time they heard about organ donation was at the DMV and that they were not provided with sufficient information. One male community

member said, “The first time I think you hear about it is at the DMV. Nobody should ever learn anything there other than to drive. It’s just very, very odd that that was the first it of knowledge I gathered.” A female community member said, “I think the first time that I even heard about it was at the DMV when I checked the little box. And other than that, I got all my information from the media.” A female undergraduate student said, “when I decided to be an organ donor, I just checked the box because I knew it was a good thing to do. But I kind of wish someone had sat me down and said like let’s just talk briefly about what this actually means.”

**Suggested ways to increase knowledge.** Participants presented a number of suggestions for improving the public’s knowledge of organ donation. Suggestions included media posts, required courses in high school, and additional educational materials at the DMV. The suggestions are summarized in the following excerpts:

“I feel like the easiest way to make it more known is to like introduce it in health classes in high school. I think if you are going to try to introduce on a wide scale, you would need to start pretty young,” a female undergraduate said.

“I think the person narratives do a lot. To know somebody that needed a transplant and that having that transplant actually saved their life... to know that things like this matter makes a difference,” a male undergraduate said.

“If you give people things to read, they're not going to read it. And I'm guilty of that, too. As much as I like to read. I don't like to read pamphlets and things like that, but I will, you know, I will fall for clickbait,” a female community member said.

“I feel like it should come up in driving class if it is something you are going to encounter at the DMV. You should know what it means when you put the little heart on there,” a female undergraduate said.

“You could have a reliable, trustworthy source of information that presents and presented in a way that the lay person can understand. There may be like a checklist of some of the urban legends versus the reality.” a male community member said.

While each participant had their own idea of what would be successful, all participants agreed that there is a need for change in order to increase public knowledge on organ transplantation.

### **Participant Attitudes Toward Donation**

**Deceased donation.** Majority of participants were in favor of deceased donation. They noted that it was the easiest way to help someone that requires little to no effort. Sample quotes include: “Helping somebody else? I mean that’s the only thing that matters.” Some participants believed it was not morally right to refuse to be a deceased donor. One participant said, “It’s selfish to not give your organs to another person who needs the chance, who has a chance to live if you’re not going to live.”

A male community member noted that his medical background played a part in his decision. He said;

“I’m a big proponent of science because I graduated with a science degree, so I am totally open and for people using my body for research. Who knows, like maybe something they find in my body could help generations of people after I’m gone.”

Even though majority were in favor of deceased donation, there was a fear of quality of medical care in some participants. One male community member expressed fear that doctors would not save his life if someone needed an organ. He said,

“The world’s already overpopulated as it is. So, they may just get rid of people.”

Another male community member said,



“I guess the worry is even if you say they can take your heart or my liver, what if they don’t stop there?”

A third male community member noted that medical history affected his views on donation. He said,

“After taking a medical sociology class, I feel like that’s where my mistrust in the medical system started. Reading studies, like the Tuskegee study, I just don’t feel safe.”

**Living donation.** Participants reported mixed views on living organ donation. Some participants felt the pros outweighed the cons. One female community member in favor of living donation said, “I don’t want to sound like a saint or anything, I mean, I’m just trying to live my life right. We’re all in a community. And so what can we do to help each other?” Others were in support of living organ donation for the connection they might have with the recipient. One participant said, “You can connect with someone you helped. It brings two people who wouldn’t have otherwise met together.” When asked how they would feel if they could no longer participate in certain activities after the surgery, one male community member said “I mean, the process is so life-changing in so many ways that you would find other hobbies. There’s so many other things you can do in life.”

**Concerns.** Other participants had concerns about the surgery, recovery, and safety of the overall procedure. One female participant said, “Anytime you go in for a surgical procedure, you risk death. That would be the number one big risk. After you make the decision to donate, it’s not like you can factor that in.” As for the recovery process, one male community member noted the negative effects of having to take time off of work: “The reality of the world we live in is that you need money in order to live. The longer you’re in recovery, the longer the time you’re not

working. So even if they aren't outright charging you to be a decent human being, there is that financial and professional costs that you might have to be considerate of."

### **External Influences on Participant Attitudes Toward Donation**

**Roots of participant views on donation.** Participants reported that there were three roots of their views: family, religion, and culture. One female community member said, "I think my views developed from my family. I just knew my parents were organ donors from ever since I could remember, so I knew I would be an organ donor." Another participant shared a similar story and said, "As a result, I would say it was more by default."

Some individuals felt that religion played a part in their decision to be a donor or not. One male community member said, "Even though I'm not heavily religious, I think you came into the world with all of this, you want to leave with all of it. So, it took some convincing." A female community member said, "My views, growing up... religion had a big influence on it. I think things shifted when we actually had somebody in the family who needed a transplant and we looked into those options."

In regards to culture, one participant said,

"I had a very humanistic philosophy around me as I grew up. Which basically... even though we were poor, we'd still donate blood and donate cans to the food drops and stuff. So, when it came time to get my driver's license, I knew I would be a donor."

**Influences on participant attitudes toward donation.** Participants noted that family, friends, loved ones, and healthcare professionals would influence their decision to donate. Family was reported as having the greatest influence on participants. One female undergraduate said, "My parents definitely made me want to donate." Another undergraduate participant said, "If I had to make that choice, then my family would influence me a lot."

Focus group participants had a range of views on the influence of their friends. One male community member said “I probably wouldn’t ask a friend. It’s not their opinion, it’s not their thoughts. I feel like I’d be more in regard to listening to family than friends.” Another community member said, “I think it’s too personal of a decision to base it off a friend’s opinion. It’s my own personal choice, so I don’t think a friend would have much of an influence.”

As for healthcare professionals, there were varied views. One female community member said, “I will do my own research. I will fact check what they’re saying. I’m not just going to do something because somebody in a white coat told me it’s okay.” Similarly, someone said, “Some of the people in the white coat don’t even know what they’re saying half the time or know what they’re doing half the time.” One female community member said that a healthcare professional’s opinion would greatly influence them. She said,

“If a doctor said, you know, organ donation saves lives... I would trust them because I think they would be telling me that from data, or a study.”

Some participants felt they would not consult anyone when making their decision. For example, one female community member said,

“They type of person that I am, I don’t want anybody to try to alter something that I’ve already decided on. I would read stories, read reviews, but to physically talk to anybody? I wouldn’t.”

### **Situations that Effect Likelihood to Donate**

**Societal Expectations.** Participants reported that that they do not feel there are different expectations for women and men when it comes to organ donation. Some participants did report that they felt it was a societal duty to donate their organs, especially after death. One female community member said, “You have to think about keeping it going. If somebody gave you their

organs, it's only right for you to give your organs away when you die, too." Furthermore, many participants felt a pressure from society to donate to relatives or close friends, with one participant revealing that he would feel guilty if he did not choose to donate to a family member in need. One participant said, "I feel like society doesn't really have that have the information that we need, like we said earlier. So, they're just like, you should be [a donor] even though you don't know completely know where it goes to. So I feel like it's kind of like the blind leading the blind." Another female community member expressed that she does not think society in the United States expects individuals to donate to those they do not know, especially when considering living organ donation. She said,

"It's nice if you want to be an organ donor. But, we are not... we're not encouraged, culturally speaking, societally speaking, to really care about anybody all that much except us and our own. Unfortunately, and it shows all over, you know, our great land."

**Circumstances Affecting Decision to Donate.** Participants reported that a number of situations would affect their likelihood of donating an organ including closeness, age, and racial/ethnic minority status. Most individuals said that their decision would depend on how close they were to the recipient, especially when considering donating to friends and family. One female community member said, "I was to be a living donor, I feel like it would be easier to justify someone who's closer to me." Another female member of the community said, "It would take a person very close to me to influence me to do that. I think a sibling, parent, kid, life partner."

The age of the recipient also proved to be a critical component in one's decision to donate, saying things like, "the only thing that might affect me is the age of the person. You're like 99 versus nine...At 9, that's just not the way you're supposed to go." Many mentioned that

they felt it was the “default” or “natural inclination” to donate to younger individuals, with one participant saying “they still have their whole life in front of them.” A male community member said, “It may be wrong to sit here and say this, but the child has more chance. They have the longer life frame anyways.

Participants reported that gender did not have an effect on their likelihood to donate, saying things like “a liver is a liver.” One female community member said, “I don't really think that demographics matter to me, as long as I'm a match for a person. And that is hard to find, like across gender or race. But if you're match, you're match, and I think that's great,” That being said, several participants stated that they would want their organ to go to a minority, or person of color. One female community member said,

“I would want to donate to people of color because they have a more complicated history with organ donation. I think that that might incline me a little bit more because they would probably have less family members open to even being tested because of the complicated history of people of color and medicine, especially like invasive type medicine.”

Another female participant shared similar feelings, saying

“I would prefer my organs go to somebody who's a person of color because we're the ones that are like least likely to receive organs. We're the ones that are probably going to be like, last on the list.”

Lastly, the lifestyle choices of the recipient seemed to be the biggest factor in one's decision to donate or not. Majority of participants expressed that they would be more reluctant to donate an organ to someone who is an active alcoholic or drug abuser. One participant said, “I don't want to put myself at risk for somebody who is not going to take care of what I'm giving

them.” Another participant said, “It doesn't matter how much I love and care about a person. If they can't care about themselves, then I can't care to help them.”

### **Differences Between Samples**

As a whole, the group expressed how complex and multifaceted the decision to donate, or not donate, can be. It is important to note the differences between the groups. A pictorial representation of the differences is available in Appendix C. Participants in the student focus groups had more positive views toward donation and their decision to donate was more influenced by the age of the recipient. The participants in the community focus group felt there was a greater need for public education on organ transplantation and were more influenced by family when making the decision to donate or not. Additionally, they were more influenced by the recipient's lifestyle choices.

### **Discussion**

The current study aimed to answer the following three questions: (1) What do people know about organ transplantation? (2) What factors influence attitudes toward organ transplantation? (3) Are there certain scenarios where people are more likely to donate to others? The findings from the 14 focus groups answered these questions by identifying knowledge, attitudes and scenarios that promote or hinder organ donation.

The focus groups suggest that knowledge of the transplant process plays a critical role in one's decision to donate an organ and that further efforts should be made to make sure the public is more educated on this topic. The findings from the focus groups also suggest that individuals may have different attitudes toward living and deceased donation. These attitudes may be influenced by external factors like family, religion, and culture. Furthermore, certain scenarios may make an individual more or less likely to donate an organ. In looking at differences between

groups, the findings reveal that there may be generational influences that affect whether participants may choose to donate or not.

In terms of attitudes toward transplantation, these findings are in line with that of Rumsey and colleagues (2003). These researchers found that four variables impacted attitudes toward donation: education of the transplant process, knowledge of someone who donated an organ after death, knowledge of someone who received a donated organ, and religious beliefs (Rumsey, Hurford & Cole, 2003). These were all found to be variables impacting attitudes in this study. However, our focus groups also found additional variables such as societal expectations and deep-rooted family beliefs. This suggests that the decision to be a donor is complex and affected by many factors. It is also important to highlight the influence of the age, race, and lifestyle of the recipient on an individual's likelihood of donation. These were factors that were brought up in all fourteen focus groups, emphasizing their importance and the need for further research on these specific phenomena.

The findings regarding knowledge of transplantation were also consistent with previous research. For one, the findings mirrored Irving et. al (2012) that found individuals acquired much of their knowledge on the donation process from television shows and media. Participants in the current study reported *Grey's Anatomy*, comedy segments, and soap operas as their source of information on donation. The current study findings were also consistent with previous research that having knowledge of the transplantation process is associated with a more positive attitude toward organ donation (Rumsey, Hurford & Cole, 2003). Participants in the current study noted the need for earlier intervention and education to potentially increase public willingness to donate organs. Participants noted the knowledge gap as a perceived barrier to organ donation, which is constant with results from Marqués-Lespier and colleagues (2013). Lastly, the results were also

consistent with past research in that the participants of this study also noted they would like to know more about the donation process. This was something that all 59 participants mentioned in this study.

This study has several important limitations. For one, many individuals in the community focus groups were younger, so there was not enough variance in age to reveal potential generational influences. This limited our ability to draw conclusions about differences in age groups and generations. Another limitation is that people's comments may be skewed based on the comments of other participants in the group. For example, if three participants were expressing support of donation, a fourth participant may have felt pressured to answer the same way even if he or she was against donation. There is high social desirability with a topic of this nature. Furthermore, some perspectives were underrepresented because not every participant addressed every question in the conversation. As aforementioned, community sample demographics were not reported due to COVID-19 interruptions. Lastly, also due to COVID-19 interruptions, I was unable to report exact reliabilities in the results.

While previous studies have produced meaningful findings, it is important to note that these studies have not focused on specific scenarios nor specifically addressed living organ donation. There are a number of strengths of the current study that make its findings significant. For one, this is the first study that addresses attitudes towards both living and deceased donation in the United States. The focus groups revealed that many individuals have different attitudes towards living and deceased donation, emphasizing the importance of looking at both types of donation. Furthermore, this is the first study to look at how certain scenarios affect an individual's likelihood to donate an organ. This is vital information that could actively work to



reduce the gap between the number of people on the waitlist and the number of people donating organs.

In the future, the findings generated from this study will inform a list of items which will be used to create a measure of public perceptions of transplantation. Future research should look at groups of different ages in order to draw conclusions about differences in age groups and generations. Demographics should be gathered from all participants to use for later analysis. Future research should also continue to look at knowledge of transplantation and how our society can increase public knowledge across all age groups.

The findings from the current study can be used to inform interventions and education on the transplant process, and potentially increase the public's willingness to donate organs. These interventions will likely start with providers, who are typically responsible for relaying information regarding organ transplantation. Additional programs in schools and Driver's Education courses may also be beneficial for long-term improvements. The goal of future informational programs needs to be not only to provide proper information to the public, but also to create positive attitudes towards organ donation. Generally positive attitudes towards donation will help reduce the gap between the number of individuals waiting for an organ and the number of organs donated.

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## Appendix A

**Focus Group Protocol****Introduction:**

Thank you all for coming today/tonight. My name is [Focus group moderator's name] and I am [position] at the University of Richmond. Assisting me today is [co-moderator's name], [position]. Thank you for agreeing to participate in this study. The information you provide will be very useful in helping us understand the public attitudes towards organ donation and the factors that affect these attitudes.

**Description of Focus Group:**

To begin, I would like to give you an overview of how this focus group will work. As you know, the focus group will last for about 60 to 90 minutes. During this time period, I will ask you some questions about your knowledge of and opinions on organ donation. While I encourage you to draw on your experience, we do not need to know any specific details of your medical history. The goal is for you to discuss the questions as a group. The most important information will come from the range of everyone's thoughts and ideas. It is very important that everyone speaks their mind and participates, particularly if you have a different perspective from others in the group. There are no "right" or "wrong" answers to the questions. We are interested in the full range of perspectives. My role is to help facilitate the discussion of this topic. I may ask specific individuals about their thoughts or ideas if they have not had a chance to participate very much in the discussion. I also may have to interrupt someone to ask that we get everyone's opinion or to move on to another topic. This is to ensure that we get everyone's views on all the questions in the relatively short time we have together. Another important ground rule for this meeting is that we will respect the privacy of all group members and keep the content of our discussion confidential. We will call each other only by first names, and your verbal and written comments will be kept strictly confidential. I will be audiotaping the discussion, and you may see me taking notes. These steps are necessary for us to accurately record what is said today/tonight, but we will not include any information that will personally identify you in our notes or recordings. At any point in time, you are free to stop participating in the discussion or even leave. When we analyze our notes from this discussion, we will be most interested in what the group as a whole has to say. After we complete the analysis, we will erase and throw away the tape recording. When we publish the results of our study, no individuals will be identified. Finally, please remember that located on your consent form are the names and numbers of people you can call in future if you have questions about your rights as a research participant. Does anyone have any questions? [Answer any questions]

**Warm Up:**

Before moving on to the main topic of our discussion, I would like to set aside a few moments for introductions. Specifically, I would like everyone to tell us their first name and briefly tell us what their hobbies or interests are. Let me begin....[Moderator: Introduces herself/himself and then goes around the table.][Moderators Assistant: Will take notes on where particular people are sitting by creating a diagram similar to the room and focus group layout. Individual first names will then be associated with a numbered position in the diagram. These numbers make it possible

to follow more accurately who in the group is speaking when listening to the tapes again as well as confidentially matching forms completed during the focus group with names.]

*Topic Questions 1: Background Information and Opinions*

- What made you interested in participating in this study? (Probe: Are you interested in the topic? Are you hoping your participation will help others?)

*Topic Questions 2: Knowledge on Transplants*

- What do you know about end stage renal, liver, heart, and lung diseases? (Probe: Have you had any experience with these diseases? Are you aware of treatment options available?)
- What do you know about organ transplantation? (Probe: Do you know which organs a living donor can donate? Do you know anything about kidney or liver transplantation specifically?)
- What do you know about the organ donation process in the U.S.? (Probe: Do you know how to register as an organ donor? Do you know how recipients get matched with donors?)
- What do you think are some barriers that people might face when trying to obtain an organ? (Probe: Do you think there is a lack of viable donors? Do you think socioeconomic status affects your chances of getting a donation? What about your doctor? Or your knowledge of the process?)

*Topic Questions 3: General Attitudes Towards Organ Donation*

- What is your view on donating organs after death? (Probe: Do you think donating organs is the right thing to do? Do you think every eligible person should donate? Do you believe your religion is in favor of or against organ transplantation?)
- Explain how this view changes when you consider live donor transplantation, if at all. (Probe: Should people donate livers and kidneys more often?)
- Do you think there is any risk associated with carrying an organ donor card? (Probe: Do you think you are more likely to be subjected to sub-par care? Do you think health workers are aware of your donor status before they treat you?)
- How safe do you think the transplant process is for both the living donor and the recipient? (Probe: Would you be concerned about the surgery? Would you be more concerned about the recovery process? How likely do you think complications are?)

*Topic Questions 4: Factors that Affect Attitudes Towards Transplantation*

- Before consenting to *donate* an organ, would you take anyone's opinion into account? If so, who's opinion would be the most influential? (Probe: Do you think a parent could talk

you out of this decision? Would you move forward with the donation even without your spouse's approval? Could a physician or nurse talk you into donating?)

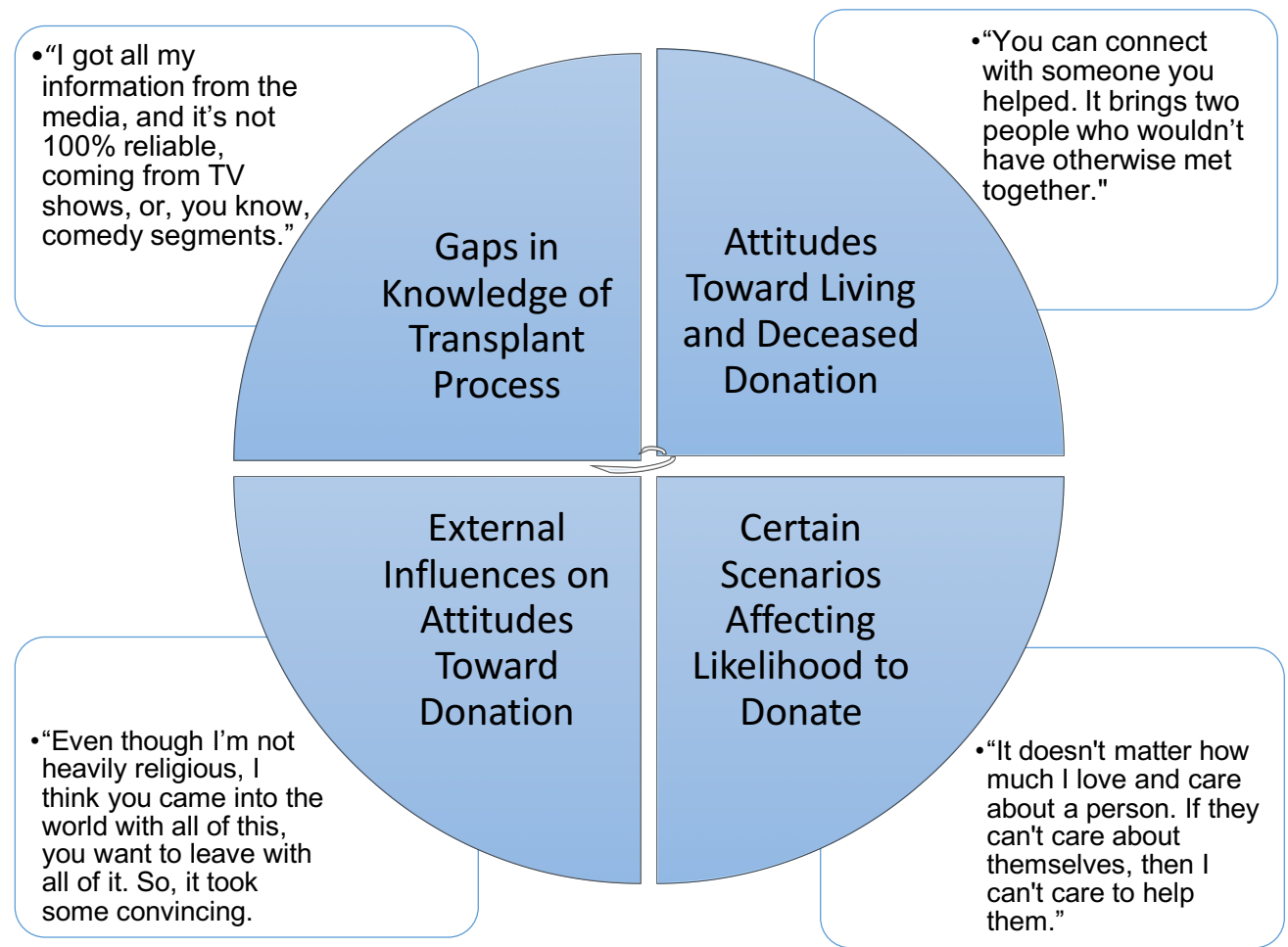
- Before consenting to *receive* a donated organ, would you take anyone's opinion into account? If so, who's opinion would be the most influential? (Probe: If possible, would you follow through with receiving a donation even if a health worker expressed concern? Would call off an organ transplant if a family member asked you to or if a religious figure if your life showed disapproval?)
- Are you personally more or less likely to participate in the transplant process due to your religion? If so, which religion do you identify with?
- Which of your family members would you expect to be willing to donate an organ to you if you were in need?
- Do you think there is a difference in expectation to donate an organ to a first degree relative (spouse, parent, full sibling, or child) versus a second degree relative (grandparent, grandchild, aunt, uncle, niece, nephew, or half sibling) versus a third degree relative (great-grandparent, great-grandchild, or first cousin)? If so, explain. (Probe: Do you feel it is your duty to donate to one but not the other? Why?)
- How would your previous answer change if the organ donation was only to improve the quality of life of the recipient rather than save their life? (Probe: Would there be more stipulations associated with donating? For instance, would you only expect a second degree relative to donate if there were no first degree relative matches?)
- In what situations, if any, would you expect a friend to donate an organ to you? (Probe: Would you expect a friend to donate to save your life? Would you expect any of your friends to do this, or only a specific person? Would you only expect this if no family members were matches?)
- In what situations, if any, would you expect a stranger to donate an organ to you? (Probe: Would you expect a stranger to donate to save your life without any compensation? Would you expect someone to donate if one of your loved ones was willing to donate to one of their loved ones?)

#### Closing:

Before we end the session, are there any other comments that you have or topics that we missed in our discussion?...If, after today's session, you think of any other comments or topics that were missed please feel free to contact me (e.g., focus group facilitator) by email. Thank you for your time and participation.



## Appendix B



## Appendix C

